

# Promoting Patient Engagement and Participation for Effective Healthcare Reform

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## Chapter 4

# Barriers to and Facilitators of Older Adult's Adherence to Health Recommendations: Towards an Engaging Two- way Health Communication

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### ABSTRACT

*Non-adherence to health recommendations (e.g. medical prescriptions) presents potential costs for healthcare, which could be prevented or mitigated. This is often attributed to a person's rational choice, to not adhere. However, this may also be determined by individual and contextual factors implied in the recommendations communication process. In accordance, this chapter focuses specifically on barriers to and facilitators of adherence to recommendations and engagement with the healthcare process, particularly concerning the communication between health professionals and patients. For this, the authors present examples of engagement increment through different degrees of participation, from a one-way/directive towards a two-way/engaging communication process. This focuses specifically on a vulnerable population group with increasing healthcare needs: older adults. Future possibilities for two-way engaging communications are discussed, aimed at promoting increased adherence to health recommendations and people's self-regulation of their own health.*

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## **INTRODUCTION**

"Patients are adherent when they do what their health professionals recommend" (DiMatteo, 2004; p. 200). When patients do not do what health professionals recommend, i.e. they are non-adherent, this may increment healthcare costs, by wasting human and material resources. In accordance, lack of engagement with the healthcare process in general and specifically lack of adherence to recommendations as communicated by health professionals, has been an important setback for health promotion effectiveness, in various healthcare systems across the world (see DiMatteo, 2004). To provide a contribution in this regard, this chapter aims to provide an overview of barriers to recommendations adherence and facilitators of people's increased participation and engagement with their own health care process.

This chapter specifically focus on the older adult's population. There are some reasons that justify this focus. Over the past decades we have witnessed an increase in life expectancy, resulting in a greater prevalence of chronic diseases, with negative impact on the health systems (Bauer, Briss, Goodman, & Bowman, 2014; Sabate, 2003). It is estimated that most of the elderly have two or more diseases (van den Akker, Buntinx, Metsemakers, Roos, & Knottnerus, 1998; Ward & Schiller, 2013), and comorbidity often implies polypharmacy and subsequent undesirable drug-drug, drug-body, and/or drug-disease interactions (Arnold, 2008). This is frequently implemented through complex administration regimens that require daily habit changes implying effortful actions and strong adherence to what the health professionals recommend (Hajjar, Cafiero, & Hanlon, 2007). In agreement, a recent qualitative review focusing on randomized controlled trials interventions for chronic diseases, found that current methods of improving medication adherence are mostly complex and not very effective (Nieuwlaat et al., 2014; see also Haynes, Ackloo, Sahota, McDonald, & Yao, 2008). This is worrisome due to the fact that has been shown that the elderly have more difficulty in following recommendations than younger people, given that they ask for less clarification and tend to be less active regarding care for their own health, being therefore more susceptible to physical, psychological and social consequences from non-adherence (Branin, 2001). This has negative consequences as non-adherence to long-term therapy in chronic diseases achieves an average of 50% in developed countries (less in developing countries), increasing health costs and decrementing positive health outcomes. To tackle this, patient-tailored interventions should include not only the assessment of patient-related non-adherence factors but also contextual factors, namely those linked to the health professionals (Sabate, 2003) and the health recommendations communication process.

However, the consideration of these contextual factors is not the focus of many patient-tailored interventions, which potentially reduces their effectiveness. In fact, the reasons for non-adherence are often attributed to a rational choice from the individual and due to their individual characteristics and not as much to their surrounding context. This is in agreement with research that found a set of individual characteristics that may explain non-adherence (DiMatteo, 2004). However, equally important are factors related to the communication process itself and how engaged the actors of this process (e.g. patient, doctor.) are in it. When these are considered, they focus mainly on the relationship between the patient and the health professional and/or on the communication content (e.g. how information is framed). However, this tells us little about how motivated the person is to engage with the process and adhere to what is recommended.

It should be noted that upon communication of health information it is expected that people initiate a process of *deliberation* - a thoughtful, careful and lengthy consideration of the information (Davies, 2009) - and then implement the necessary actions to adhere to recommendations. However, providing information alone without people feeling engaged with the communication process and expecting the

recommendation to translate into behaviours, may not achieve the desired results. The patient's engagement could be evidenced through affirmations such as "I have a question!" "May I comment on that?" or similar expressions, when faced with recommendations. However, these are less heard than it would be desirable, in healthcare settings. Not expressing their information needs and not manifesting elaboration on the health information received, may suggest lack of manifest deliberation on this information and engagement with the healthcare process. This may not necessarily evidence that the person chose to rationally distance her/himself from the process but rather that the process may not be sufficiently engaging. It is our contention that increased engagement can be achieved through strategies that may mitigate barriers and promote facilitators of people's engagement with the communication process and adherence to recommendations. Rather than having a one-way communication process in which recommendations are transmitted to the person and expected to be followed, a two-way engaging process centred not only on the person but also on the communication process, could be put forward.

With this goal in mind, this chapter first identifies examples of macro and micro level factors that may explain people's lack of adherence to recommendations. Moreover, reasons for lack of engagement with the healthcare process itself that may translate into people's lack of adherence to recommendations are identified. This will be followed by various examples through which this engagement can be increased, based both on person-centred and communication-centred perspectives. Lastly, we will discuss future possibilities and avenues for research and practice, towards the promotion of an engaging two-way health communication. In order to do this, we will focus specifically on a worldwide growing vulnerable population group with increasing needs with regard to healthcare: older adults.

## **BARRIERS TO OLDER ADULT'S ADHERENCE TO RECOMMENDATIONS**

Over the past few decades, the European institutions have encouraged new forms of social participation in various domains, to implement shared consensus towards problem solving and create stronger support for public actions. New mechanisms and methods aimed at enhancing citizenship have entailed a large variety of activities across different scales and levels of analysis and intervention. This has been manifested worldwide in the construction of new connections and interactions between governmental institutions, non-governmental organizations and citizens. Despite this new "way of doing things" that has been emerging, in the healthcare domain there is still much to do, especially concerning older adult's healthcare. Specifically, there are still a number of barriers that inhibit people's intention to adhere and implement those intentions into behaviours.

One level in which these barriers can be found is the macro level, concerning for example socio-cultural, organizational and socio-political factors. At this level, the theoretical and methodological approaches to the study of older adult's participation and engagement, has become increasingly more complex, in order to face the rapidly changing world and social actors shifting roles. Socio-demographic transformations are making older age a very sensitive socio-political issue and challenges to healthcare systems are manifested worldwide. Significant changes concerning economic resource distribution, social exclusion, the strains posed on the welfare state and the necessary measures to mitigate it, all reflect structural changes at the macro-level. These in turn, have implied profound transformations in the last century, in how senior citizens are perceived worldwide. As one of the most dramatic results, older people often feel non-competent to influence the political debate, and show low levels of collective action – e.g. through petition, protests, occupations, etc. – in different fields, including the healthcare system.

Theories concerning social and economic disengagement have sought to explain the main factors for older adults' distancing from community life. Ironically, they have also often contributed to reinforce an image of elderly passivity in the hands of policymakers. Public policies regarding retirement have particularly contributed to build an image of dependence on State's economic resources and public healthcare services (Cumming & Henry, 1961). Another related negative perception is that the elderly have reduced abilities, needs and capacities in various dimensions of their personal and social life, also contributing to this perceived dependency. These are some of the perceived characteristics associated with an elderly stereotype, implying their view as a homogenous group sharing these negative characteristics. This view has been counteracted in the last few decades, given the senior users new demands concerning various personal and social services, new senior citizen-centred approaches in public services, and increasing demands for professional expertise in health and other domains. This has compelled scholars to shift towards new approaches to ageing (Walker, 2006). Increasing awareness has been reached on conditions that lead to dependence in later life, which may be produced and reproduced by economic mechanisms and social policies. In addition, senior citizens do represent a controversial target by being everything but a homogeneous social group and scholars have growingly testified how old age is highly diverse within the associated population group. As a result, needs and capacities to participate and engage in social and political life should take into account such diversity. This should allow counteracting the perceived passivity and lack of capacities to socially engage and be more participatory, as these may work as barriers by ironically contributing to induce dependency.

To counteract the influence of the negative elderly stereotype, new perspectives on ageing have gained room in the scientific debate in the last few years. The focus on sources and resources for "active ageing" has been critically underpinning the socio-political constraints that often reinforce ageist attitudes and measures (Timonen, 2008). Fight against ageist attitudes should mean actually removing structural, social and psychological barriers in order to improve accessibility to all senior citizens, which can then decide whether or not to engage and participate. Inclusion rather than exclusion of senior citizens by removing barriers that may prevent them from making choices with regard to their own healthcare represents an issue of great relevance when acknowledging demographic trends, and risks of marginalization run through the design of ineffective public services.

Senior citizens' involvement is seen increasingly as a priority against atomized consumerism trends, potentially corroborating neoliberal needs of low-paid labour force as well as of minimization of the state in health and social care services. While so, a critical approach to "active ageing" has also made explicit the risk for further discrimination when narrating "simple" stories of autonomous senior citizens expecting to be involved (Biggs, 2001; Beresford & Branfield, 2006). In these terms, the affirmation that senior citizens empowerment can be improved through voicing their claims and directly involving them in public services, can have also counter-effects. In this regard, Gilleard and Higgs (1998) pinpoint the risk of shifting the responsibility for health from the corporate representation of the people's needs to the individual's responsibility to preserve his or her own health. The authors argue that the market language is forced into citizen's discourse to "sustain a "hyper-reality" of user involvement and empowerment" (p. 246). The authors also state that older people represent one of the most impoverished groups of healthcare users, with inequalities stemming from socio-demographic, socio-economic, geographical and other factors, which may limit their engagement and participation efforts. Moreover, lack of resources to effectively engage and participate may be a limitation, including for example lack of symmetric information and skilled/competent personal assistants (Glendenning, 2008).

Apart from this macro level barriers to the participation of older adults and their engagement in the healthcare process in general, which may translate into lack of adherence to health recommendations, other important barriers exist in more concrete contexts. These concern the communication context and associated situational factors in which recommendations are shared, from the micro level dyadic patient-health professional interaction to the macro level of communication sharing by health organizations (and other stakeholders) to citizens. From these stakeholders, experts and laypeople in general point of view, reasons for non-adherence are often attributed to a rational choice to not adhere. These are often attributed to individual factors (their goals, needs, personality, etc.), namely personal goals that determine an individual to preserve her/his quality of life (DiMatteo, 2004; Schüz, Wolff, Warner, Ziegelmann, & Wurm, 2014). Differently, macro level and situational factors that interact with these and other individual factors are less frequently seen as reasons for non-adherence. For example, the type of therapeutic regimen prescribed to a patient and the perceived available social and individual resources to adhere to the recommendation have been considered important factors. Accordingly, the probability of adherence may decrease due to barriers such as high demanding regimens (e.g. medicine intake rather than lifestyle changes) and low levels of resources (e.g. education; income) (DiMatteo, 2004).

In addition to these factors, the dyadic relationship between the person and the health professional manifested in a micro level setting, between doctors and their patients, and at a macro level between health organizations and citizens, is considered equally important. These include factors for example related to the relationship itself; the health professional characteristics (Kjeldmand, Holmstrom, & Rosenqvist, 2006) and her/his capacities to convey the information and its meaning (Davis, 1968; Davis & von der Lippe, 1968); the information content (DiMatteo, Reiter & Gambone, 1994).

Less frequently considered, are factors related to the communication process itself. In fact, it is insufficient to consider only the communicator's role (the health professional), the receiver's role (the patient) and the recommendations content (information provided), in promoting adherence to recommendations. The actual process, through which recommendations are communicated and disseminated, may also be determinant. Hence, in addition to a patient centred perspective (for a review, see Mead & Bower, 2000), a communication-centred perspective needs also be acknowledged, in order to increase the effectiveness in promoting adherence (see Mead & Bower, 2002). With regard to this, it should be noted that the interaction between individual characteristics and the way the information is perceived, may even prevent people from hearing/reading the information about the recommendation. In other words, before deciding to adhere or not, they may not even access the content of the information regarding the recommendation, because they may actively avoid it before hearing/reading it. Accordingly, it has been demonstrated that some people show a tendency to avoid information that is communicated by health practitioners (Brashers, Goldsmith, & Hsieh, 2002). For example, as shown by Gaspar et al. (2015), if an information on risk-benefits (e.g. maximum daily amount of red meat consumption) somewhat contradicts the previous information individual's had, their existing attitudes (e.g. towards red meat) and/or beliefs towards the issue (e.g. red meats consumption provides pleasure), they may avoid information that is communicated to them and not seek further information. This can occur for example, if people have positive attitudes towards a certain product (e.g. food product or food component; medicine) or perform certain behaviours, and receive information that it has risks to them.

Apart from individual factors, the communication environment itself may also contribute to people avoiding information. They may perceive health information as overly complex and feel lacking the capacity to deliberate on it, thus reducing their engagement with the information and the associated communication process (Rutsaert et al., 2015). This may occur because they feel that there is: 1) an in-

formation overload - too much information available in the “communication environment” surrounding them – thus deeming this information as inconsistent, confusing and hard to comprehend (van Kleef et al., 2006); 2) the communication context has increasingly become more complex and uncertain (Miles & Frewer, 2003; Renn, 2008); 3) there is too much conflicting information from different sources (e.g. Regan et al., 2014). This complex communication context may lead consumers to become more dependent on authorities and less engaged with socially relevant issues (Shepherd & Kay, 2012) and, ironically, more information avoidant (Gaspar, Carvalho, Luís, & Lima, 2014).

Therefore, it is essential to implement communication strategies that on one side, promote better understanding, reduce perceived complexity and are tailored to the individual's information needs, therefore facilitating deliberation. On another side, they should be more motivating and engaging, therefore reducing individual's avoidance. From these, we will focus on the second aspect, by presenting examples of strategies aimed at promoting older adult's engagement with the communication process. Ultimately, this can increase the probability of people deliberating on the information communicated by health professionals and use this information as guides to adjust their behaviour to the recommendations.

## **FACILITATORS OF OLDER ADULT'S ADHERENCE TO RECOMMENDATIONS**

### **Forms of Participation and Engagement**

Counteracting the increasing complexity of societies, participatory mechanisms have been promoted in policymaking for more effective and responsive public services (Fischer, 2003). The inclusion of social actors in a field that traditionally has barely provided spaces for public deliberation, has transformed the socio-political scenario in the last few decades. As pointed out by Arnstein (1969) in his milestone contribution regarding citizen participation, the redistribution of information, resources and influence on decision-making should be understood at the heart of these new processes. The author's analysis was framed within a specific context of struggles carried by low-income citizens and community organizations in the United States in the 1960s. The author operationalized the insights concerning participation through the articulation of a ‘ladder’ that posits eight rungs of progressive citizens' empowerment through different participatory methods, that provide a good analogy to analyse the subject of this chapter. At the bottom of the ladder we find the so-called 1) *manipulator methods*, followed in an increasing level of participation by 2) *like-therapy participation*, 3) *information*, 4) *consultation*, 5) *placation*, 6) *partnership*, 7) *delegated power*, and finally, 8) *citizen control*. Through means of this ladder, the author sought to capture the diverse degrees of power that citizens can either be given or self-attribute in public decisions. As manipulator and like-therapy methods are inserted at the very bottom of the ladder, the author advises against considering them as forms of genuine participation. Subsequently sets Information as key to empowerment, though not sufficient for the purpose of citizen participation and empowerment. Arguably, Arnstein describes the following approaches, from consultative to citizen-centred, in terms of increasing control over decision and, therefore, empowerment. Developed explanations of each “ladder” will be presented next.

From this contribution, numerous authors have since debated the opportunity to rely on this ladder, to advance it or contest its theoretical and methodological application. Pretty (1995) for example, improved the ladder by distinguishing: manipulative and passive participation whenever the decisions have already been taken; consultation, representing material incentives making people participate by



contributing with resources; functional participation, whenever the aim is efficiency and cost reduction, after the main decisions have been made by external agents; interactive, when local groups take control over decisions; and self-mobilization of people controlling the resources and taking the initiative independently of external organizations. Fung (2006) also criticizes Arnstein's ladder (1969) and argues that different contexts demand different typologies of participation which cannot be defined as bad or good in a "normative" sense. They should be rather seen as a complex combination of different scopes, extents of authority, and modes of communication and decision. Differently, consistent with Arnstein's proposals, redistributing powers, gathering new agents for shared projects, reconsidering the borders between public and private, regenerating trust towards political institutions, are some of the complex issues emerging through participatory processes in the last few years (Sintomer, 2007). Participation can be designed in very different ways and this has opened to a lively debate in social and political sciences. The power exerted within the participatory initiatives may take different forms depending on dynamics among participants as well as on the relation between participants and institutions (Nie & Verba, 1975; Gaventa, 2006; Falanga, 2013, 2014).

Although being a classical approach to citizens' participation developed decades ago, we think that Arnstein's (1969) "ladder of citizen participation" provides a clear analogy to propose different ways through which older people can participate and be engaged in the area of health recommendations communication and promotion of patient's adherence to health programs. In our view, this area may be overly dominated by a one-way informative approach and thus, various forms of participation can be followed, moving forward towards a two-way communication. Some of these examples will be given next. From these, we will specifically focus on the last five levels of Arnstein's "ladder" (1969) from Consultation to Citizen Control. We will not consider the first three levels - (1) Manipulation, (2) Therapy and (3) Informing – as the first two are considered to be "substitutes" for genuine participation, and the third as representing only one-way directive communications. Differently, Consultation and Placation allow the distribution of a relative – yet low – degree of power. On one side, consultative approaches are concerned with collecting people's voice, opinions and feedback to devise possible changes. When citizens hear and are heard, the process of interaction between health professionals and patients is likely to enhance models for two way communication. On the other side, placation implies a more pro-active role for all the agents, in shedding power from established owners to recipients. However, in both cases no assurance is given on the impact of patients' views over final decisions. It should be noted then that, although Consultation and Placation provide approaches with the potential for increased citizen participation and engagement, they reflect a degree of tokenism in which an illusion of power for those "have-nots", is created. Hence, they may often be more of a barrier than a facilitator to citizen participation and engagement, as they provide this "illusion" and may prevent higher levels in the "ladder" of being achieved. Differently, from Partnership to Delegated Power and Citizen Control, we find increasing levels of participation and shared decisional power, where people can negotiate and make changes in the process and ultimately self-manage their health behaviour in a way that allows them to effectively adhere to recommendations.

It should be noted however, that we draw on Arnstein's "ladder" (1969) only as a way to provide structure to the chapter, with regard to the presentation of adherence facilitators and also because it is a much known analogy to citizen participation, which allows making arguments clearer by drawing on familiar examples. More recent approaches (e.g. Collins & Ison, 2006) have criticized Arnstein's "ladder" (1969), seeing it not as much as a participation approach but more as a social learning process towards true participation. Hence, next we present examples of facilitative strategies that may allow achieving increased participation/engagement, based on Arnstein's proposal as a familiar approach in this regard.

## **Consultation**

In a broad sense, consultation implies the invitation made to citizens for sharing their opinions (Arnstein, 1969). This can take various forms, from more formal or informal interviews to more scientifically validated forms, including for example experimental and non-experimental studies on people's adherence to health recommendations. For example, through this, patients can be "consulted" to determine the facilitators and barriers to this adherence. We will next present some examples of studies held exactly with this goal in mind.

Considering the example of medical prescriptions and regimes, in accordance to Osterberg and Blaschke (2005), health professionals have been contributing to poor adherence to medication. This is due to failing to explain the drugs benefits and side effects, not taking into account the lifestyle of patients, the cost of drugs, prescription of complex administration regimens, and establishment of weak therapeutic relationships. All these function as barriers to adherence that should be taken into account if consultation is to be implemented. Given these findings, it should also be noted that communicating of information about medication prescription to elderly patients, should be carefully undertaken. Accordingly, assessments should be implemented with the goal of collecting information and feedback about the most prevalent factors in non-adherence. This should take into account not only the patients but also their surrounding contexts and its various elements (e.g. health professionals; communication content and framing) (Krueger, Berger, & Felkey, 2005; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001).

In order to overcome the problem of patient's poor medication adherence (MA), various studies have been put forward, that we consider fitting the category of Consultation. In most studies, the MA factors were separately analysed. Nevertheless, through the experimental research model (Lamiell, 1995) it is possible to simultaneously study factors and processes that influence MA, namely the factors' relative weight and also between-factors interactions. The therapeutic relationship itself has an impact on MA as it generates less or greater trust in health professionals. Particularly the trust that patients have in health professionals was conceptualized by Hall, Camacho, Dugan and Balkrishnan (2002) in association with five factors: loyalty, competence, honesty, confidentiality, and global confidence (the "soul" of confidence, combining elements of some or all of the previous factors). Trust is generated in the reciprocal relations of the consultation process. Unfortunately, many health professionals are not formally trained to detect whether patients are adhering to medication and do not know how best to intervene when patients seemingly do not adhere to medication (Marcum, Sevick, & Handler, 2013). Also the non-compliance to prescription regimens may generate frustration in health professionals, leading to paternalistic attitudes (Wens, Vermeire, Van Royen, Sabbe, & Denekens, 2005). On the other hand, the health professionals' perception of drug adherence can influence prescription standards and lead to failure in the therapy intensity (el-Kebbi, Ziemer, Gallina, Dunbar, & Phillips, 1999; Roberts & Volberding, 1999; Huizinga, Bleich, Beach, Clark, & Cooper, 2010). For example, in the pre-prescription phase, HIV/AIDS's health professionals may make decisions based on their beliefs about the patient's likelihood of adhering to therapy, exploring their current psychosocial situations (Roberts & Volberding, 1999). In post-prescription phases, they may often suspect the emergence of non-adherence, even when patients admit to comply with therapy. Then, if professionals have difficulties in dealing with this perceived distrust in patients, this may induce a lack of exploration of reasons for non-adherence: this bias is an important barrier to in-depth adherence communication (Barfod, Hecht, Rubow, & Gerstoft, 2006).

The drug administration regimen complexity (RC) has also been found to determine adherence: the more complex the more likely it will not be followed, since simpler administration regimens tend to

have higher adherence (Matsui, 2013; Russell, Conn, & Jantarakupt, 2006). The RC is related to the number of prescribed medications and it has a negative impact on MA, particularly in elderly patients, who on average receive more prescriptions than other age groups. This is an important issue because the elderly tend to be more vulnerable to cognitive deficits and seem to be less capable in decision-making processes based on information that requires in-depth analysis (Finucane & Lees, 2005; see also Diniz & Amado, 2014). Cooper et al. (2005) showed that the cognitive decline by itself does not decrease adherence but together with a resistance to care, may decrease adherence. The authors add that this association is typical in people with poor insight into their dementia, implying that health professionals can improve MA tailoring interventions to the dementia degree. Another relevant finding regards financial factors, namely the existence of low financial resources which have a negative impact on MA (Safran et al., 2005). In general, it is not mandatory for health professionals to ask patients how they pay for medication. For example, in the study of Ried (2010) the cost of medication (CM) played an important role on adherence in patients who have low adherence rates, but not in patients who normally adhere to medication, suggesting that despite financial difficulties, patients are influenced by their health beliefs. Thus, the relationship that patients establish with health professionals is important as it can influence the perception of valuation of medication prescription. Finally, the severity of clinical condition (SCC) is also important factor. When a clinical condition that poses a risk to life is communicated, it generates an aversive feeling, usually of great intensity, which raises feelings of dread. However, despite this, dread may also act as an emotional persuasion factor invoking risk mitigation measures (Sjöberg, 2002). For example, a person who considers her/his illness to be serious but controllable through medication will have a more adaptive response to the threat that the disease may represent (Schüz et al., 2011).

These MA determinants were mainly studied, separately, within quantitative, correlational and clinical experimental research models (Lamiell, 1995). These have included direct measures of adherence such as pill intake and medical tests; direct forms of feedback collection (e.g. through verbal reports collected from interviews or focus groups); and indirect measures of adherence and its determinants (e.g. risk perception) such as patient self-reports, patient spouse reports, medical reports and questionnaires. These are often mentioned in the literature as some of the most commonly used techniques to assess MA (Krueger et al., 2005; Osterberg & Blaschke, 2005; Vermeire et al., 2001). However, experimental research model use (Lamiell, 1995) can be advantageous to simultaneously study factors and processes that influence MA. An example of this is provided in a study developed by Santos (2014) with elders without depression and cognitive impairment, in a non-clinical context. Factors such as SCC (severity of clinical condition: normal, serious, life threatening), CM (cost of medication: 75€, 150€, 225€, matching a 15% proportion of 500€, 1000€, and 1500€ monthly income, respectively), RC (regimen complexity: complex and simple), and TC (trust in clinicians, operationalized as clinician experience: experienced vs. highly experienced), were analysed through a randomized sequence of 18 scenarios presented on a computer. Each scenario conveyed the same cover story depicting an ordinary medical consultation, wherein a fictitious elder patient had to decide whether to adhere to a new drug prescription for a heart condition, as suggested by a doctor. The participants reported how much they thought the fictitious patient was willing to adhere, on a Visual Analogical Scale ranging from “not at all adhering” to “totally adhering”.

Results showed in both RC but not in both the TC, that SCC and CM had a main effect on adherence, and that their interaction effect added up until a “serious” level of SCC was achieved. The latter represented a ceiling effect of SCC precluding a further impact of CM even at its highest level (225€ among the patients' current expenses). This interaction means that CM strongly determined the adherence but

in a situation of risk in which life is of concern, it progressively took less importance. Irrespectively of the CM, it appeared that the elderly (and people in general) possess affective rationality (Slovic, Finucane, Peters, & MacGregor, 2002; Slovic, Peters, Finucane, & MacGregor, 2005) implying that when facing a hazardous situation, the financial aspect becomes less important. Moreover, despite financial difficulties, patients may be influenced by their health beliefs (Piette, Bears, Rosland, & McHorney, 2011; Ried, 2010), which makes possible to decrease the therapy failure, even when there is high cost for drugs. Another finding was that participants previously clinically diagnosed with heart condition showed more willingness to adhere when confronted with trials combining prescribed complex regimen with highly experienced clinician, than trials simply with an experienced clinician.

The studies examples and the methodology underlying them, have theoretical and practical potential for designing communication protocols with the goal of enhancing MA among the elderly. Using a discourse similar to Santos (2014, pp. 52-53), health professionals can discuss the cost of drugs with patients, knowing that similar importance judgments are made for both “serious” and “life threatening” conditions of SCC. The implications of the affective process on risk communication, drawing on how the different levels of medical condition severity are presented to the elderly, may also help outlining strategies to increase adherence. However, information manipulation concerning the levels of disease severity is ethically unacceptable, even though it might be a benefit: its effect can only occur upon a full demonstration of appropriate information transparency (without excessive technicalities, and pointing out real consequences). At the same time, it should be associated with the value of decision-making autonomy of the patient, a dimension needing to be accounted for in MA.

## **Placation**

Although important, consultation is not enough by itself to motivate elderly people to achieve higher levels of involvement and participation in health promotion programs. Through Placation, a form of consultation may also be implemented, although in this case people begin to have some degree of influence (Arnstein, 1969) over the healthcare process and specifically over the communication process. Although placation is not a true two-way communication between health professionals and people, it may be step towards its implementation. The reason for it not being a true two-way communication is related to the “power balance” given that the power to decide and adjust the communication process still lies with the communication managers (decision makers) and health professionals. Nevertheless, it can allow for example designing of communication adapted/tailored to people’s everyday “language” and increase the effectiveness of healthcare communication in real time and as it develops. This may allow empowering both the health professionals and communication recipients (i.e. patients and general population). The feedback resulting from this interaction can be further used to provide input for communication managers and health professionals with valuable insights, allowing them to adjust future communication strategies and better manage their communicational resources.

The role played by both the health professionals and the communication recipients is very important, as they influence not only the way that communicational processes are shaped but also the building blocks towards a stronger involvement and participation. This can be achieved through the trust building and creation of a functional two-way practitioner-recipient channel, set to achieve relational and communicational goals. To start building this trust, it is important that health professionals are ready and able to listen and value the reactions and inputs/feedback shared by the recipients, upon receiving information. Hence, this process should be seen more as a form of social learning or co-constructed learning process

that allows a convergence of goals, expectations, understandings and behaviours (Collins & Ison, 2006). This may allow the progression of all people involved towards higher levels of participation and mutual learning.

Examples of this communication-centred perspective are found in the literature, representing a form of placation. For example, a simple way for people to provide feedback is through the expression of comments, opinions, and questions. However, people are not used to do this nor are the health professionals used to promote this “habit”, when some sort of information or other stimuli is presented. It is therefore more frequent to find placation in the form of feedback acquired through people expressing their views/opinions on a certain subject(s) and not as much from feedback acquired through questions, opinions, and comments produced by people in real time. Accessing the later may allow tailoring communications to people’s actual and perceived information needs, rather than to the information the health professionals perceive that people need. There are examples in the literature concerning tailored interventions that aim for this, such as for example the Adherence Therapy (Daley, Deane, Gray, Hill, & Myint, 2015). Although there are examples, these are more often found in the scientific literature rather than in practice.

To better understand the importance of listening to and valuing the feedback shared by people when confronted with information, we must look into the concept of Deliberation. Deliberation should be seen as a discursive knowledge construction and sense-making process, that is the basis for an informed decision-making with regard to health (namely risks and benefits). By promoting deliberation upon receiving information, people may compare the “new” received information with pre-existing information. This can allow for an “internal debate” with herself/himself and his/her own thoughts and weighing up information and (risk-benefit) trade-offs. By doing this, the creation and integration of new knowledge, new understandings, new decision and acting strategies may be achieved (Rutsaert et al., 2014; Barnett et al., 2008; De Cindo, Macintosh, & Peraboni, 2010). Under this assumption, comments, opinions and questions emerge as “deliberative markers”, which can for example allow a qualitative analysis of this knowledge construction process (Marcu et al., 2014; Rutsaert et al., 2014). In order to foster participation and involvement, health professionals could see these deliberative markers as feedback, valuing it as a way of understanding people’s deliberative processes (their “way of thinking”) rather than discarding it as a sign of lack of information. It should be noted however, that deliberation is an inherently heterogeneous process that may differ between different people with different life experiences, knowledge, socio-cultural and educational backgrounds. In addition, this type of feedback may also allow understanding the themes and strategies used by people to construct meaning, allowing health professionals to adapt their language and explanatory examples given, to the person’s worldviews and cultural and educational backgrounds. This can be done for example by providing meaningful and familiar examples that can help people to understand information. This is important because when people use prior existing information to scrutinize new information, they tend to use the most readily accessible information and analogies to other pieces of information that are familiar to them and somewhat perceived as similar to what they know (see e.g. Morgan, Fischhoff, Bostrom, & Altman, 2002; Peters, Hess, Västfjäll, & Auman, 2007). This procedure may promote an initial form of participation and involvement, by eliciting comments and questions and ultimately, allowing the co-construction of the communication process. For example, in an exploratory study that addressed the deliberative processes upon confronting the participants with a health recommendation with regard to red meat consumption (Domingos, 2014) we found that very few participants used the numerical information conveyed by health authorities. Instead, deliberation was based on information on their own past behaviours and behaviours of others (e.g. family members and neighbours), used for social comparison.

Lastly these aspects should also be seen from the point of view of new forms of expression that are available nowadays. The emergence of the internet changed the way people engage with information, which combined with the increasing use of communication and information technologies in healthcare settings, implies that more and more people rely on health information conveyed by electronic communication tools. Particularly, the potential of social media to improve healthcare, health communication and health information sharing should not be underestimated (Chretien & Kind, 2013) for all people, including the elderly. Online information seeking habits and social media comments, opinions and questions should also be taken into consideration, and can be further used to understand and tailor communication to people's needs. It is important that health organizations, health program managers and health professionals follow this trend, by providing safe digital environments. In these, people may seek accurate information to address their health concerns, produce their own user-generated content, exchange their comments, opinions and questions with expert professionals and others, therefore satisfying their needs while building trust. Hence, social media data can be analysed and used to provide another form of placation, helping to move forward towards higher levels of participation.

## **Partnership and Delegated Power**

While consultation and placation are valuable sources of information for adapting communications and health programs to older adults, the power that older people have is still low. This is because there is no assurance that feedback will actually be implemented into healthcare changes and in the communication of recommendations. In this regard, it should be noted that the concept of participation is visibly intertwined with different fields of older adults' daily life. When focusing on the effective integration of senior citizens into social and familiar networks, as well as into community life, we should better consider the impact over individual and collective standards of quality of life (Lavasseur, Richardc, Gauvinf, & Raymondi, 2010). Health and social care systems have often promoted new mechanisms for the involvement of senior users. The rise of more sophisticated and diverse consumerism, new demands from service users and carers, new questions concerning professionals and experts towards involvement-oriented practices, make participation of senior citizens a matter of high and global significance (Scourfield & Burch, 2010).

Opportunities for activity imply looking at the social, economic and political structures that either facilitate or constrain senior citizens' involvement in public life activities. Activity can also refer to physical abilities and continuity in labour force, as well as social, economic, cultural activities and participation in civic affairs (World Health Organization [WHO], 2002; European Commission [EC], 2012). In this regard, the International Classification of Functioning, Disability and Health (ICF), as provided guidelines for assessment, placing emphasis on the involvement of people in need of technical and/or human help to accomplish daily activities in life situations (WHO, 2001). Based on this, participation should be analysed with validated measures and focus on the degree to which a person fulfils roles, has relationships, and displays community presence as well as other actions that can be witnessed by an observer. In this regard, activity if seen (as a mere execution of tasks) is overtaken by participation (meant as functioning beyond impairment and performance, i.e. control of one's own life), even if the person may not actually do something themselves (Dijkers, Yavuzer, Ergin, Weitzenkamp, & Whiteneck, 2002).

Older people's access to organizations, institutions and agencies that have a role in their lives, in a way that may allow them to "have a say", is a primary challenge (Carter & Beresford, 2000). Looking at the different forms of older adults' participation through the lens of Arnstein's (1969) ladder, it is evident how the higher rungs – the delegated power and citizen's control – are not the most common experiences

worldwide. In most cases, participation is mediated by organizations that provide the possibility to exercise their democratic rights through representatives that promote their material and immaterial interests. These organizations are mainly voluntary agencies, community groups and political parties, which have been emerging in the last few decades, attributed the role of wide range of functions on behalf of older people. Such functions mainly concern advocating, acting as pressure or lobbyist group, facilitating the interaction among other senior citizens' organizations, providing services to senior citizens, etc. Service user organizations generally reflect the right of service users to speak and act on their own behalf but have developed in different ways and with different strategies. Often these operate either independently or in partnership-based arrangements with State and social service systems (Beresford & Branfield, 2006).

Organized or non-organized forms of senior citizens' involvement can both encourage new forms of planning ahead for the elderly's own health and wellbeing. Cook and Klein (2005) argue that involving the public in services moves towards developing partnership with patients in the planning of services. Evans and Vallely (2007) state that the "Opportunities for service users to be involved in decisions about care delivery and service development on an ongoing basis are increasingly seen as central to a sense of well-being." (p. 15). The active involvement of senior citizens was considered an asset which potentially increases the chances of success of service planning and care management process. The Program "Better Government for Older People", run in United Kingdom at the end of the 1990s, has argued in favour of the need to go beyond mere consultations through a capillary implementation of new initiatives at the local level in Europe (Vegeris et al., 2007). On the one hand, the experiences carried out in UK reflect that health and social care issues predominate in the Local Authorities' thinking about older people's participation. In other words, the business and the context of major interaction are directed towards senior users of such services. More traditional models of consultation and information sharing were favoured by the Local Authorities, though in numerous cases the new forms of interaction led to the implementation of "wider and deeper" forms of engagement (Farrington, Bebbington, Wellard, & Lewis, 1993). All in all, the most innovative forms of engagement and positive effects on seniors' involvement typically contained elements of informality against business-like settings. This outcome confirmed that care services' users can be more effectively involved by opening to their role as "decision-makers" concerning their own health. In this regard, Barnes and Bennet (1998) assumed users' will to be involved not only in final decisions but also in "framing" the problems, as the basis to undertake participatory researches and citizen-led programs evaluations. Hayden and Boaz (2000) argued that the Program "Better Government for Older People" has ensured that healthcare services reflect the needs of older people and raised the awareness concerning the positive contribution of their participation. Nevertheless to actively engage older people in new democratic processes, some type of formal organization is nevertheless required.

With regard to the direct control exerted by senior citizens in self-regulatory forms of organization, one of the authors of this chapter is currently involved in a European Commission-funded Project aimed at identifying participatory practices in policymaking<sup>1</sup>. A small part of the evidence collected through this Project sheds a light on direct involvement of older adults in public services. Among them some interesting practices are being carried out in healthcare systems. The case of the Andalusia region in Spain, is a clear example of how senior citizens and users could take part in their well-being. There are more than 3,500 social centres regulated by the Regional Ministry, which work on issues relate with child care, drug addiction, disabilities, immigration and elderly people. Services are provided in coordination with local authorities and in collaboration with local NGOs. Almost two thousands centres are devoted also to senior citizens and The Regional Government of Andalusia issued the Decree 72/2012 which transformed the "Day Centres" for older people into "Active Participation Centres". These Centres

promote a new form of healthcare service delivery by including senior users in the General Assembly board and elect their representatives within the Management and Participation Board of the Centres. It means that beyond promoting care, services and social activities, these Centres provide the tools to make senior citizens' voice heard, in decision-making. The Centres deal with a wide range of activities, including cultural and leisure, as well as ICT training, and advice on juridical matters and other services for low income seniors. Activities and workshops are decided together with the Regional authority and all services are discussed in the General Assembly and decided by the Management and Participation Board together with the Direction of the Centres.

Mere forms of consultation may not be effective if the results are ignored or even used to legitimate a pre-set agenda. Both UK and Andalusia cases make a point on senior citizens' role in decisional processes that directly affect them. The "Better Government for Older People" program in the UK owned a large variety of approaches that resulted into very different outcomes. The need to go further in providing decisional power to older users has been clearly pinpointed as one of the results by the people involved in the local experiences (Vegeris et al., 2007). At the same time, the ongoing case of Andalusia demonstrates that is possible to include older people's "voice" in the management of health and care services. While so, it also demonstrates that the socio-political context wherein these experiences take place plays a crucial role. In the last two decades, Andalusia has been one of the most "active" regions in Europe, with regard to the implementation of participatory mechanisms in policymaking.

### **Barriers and Facilitators across Different Levels of Participation and Engagement**

Given the different "ladders" that may be crossed to achieve more effective and "true" forms of elderly participation/engagement, we now synthesize the barriers mentioned before, by considering their detrimental role in this progression. These are shown in the table 1 below.

It should be noted that our goal in this regard was not to be exhaustive in finding all possible barriers but rather to present a wide diversity of reasons for non-adherence, at macro and micro levels of analysis.

### **TOWARDS THE PROMOTION OF AN ENGAGING TWO-WAY HEALTH COMMUNICATION**

In the examples given above, various forms of older adult's participation in the healthcare process we presented. These went from different levels from consultation – including direct and indirect information and feedback gathering – to "partnership" and "delegated power" in which older people may have a shared decisional power, can negotiate and make changes in the healthcare and communication process. All of these were presented as strategies through which participation in the healthcare process may be increased, implying a reduction of barriers to and increment of facilitators of older people's adherence to health recommendations. From all of these, however, the last step (8) of Arnstein's ladder (1969) – *Citizen Control* – is still unaccounted for. The power implied in it would allow people to have an active role in their care, for example by self-managing their behaviours, cognitions and emotions, to more effectively adhere to health recommendations.

There are various examples in the literature (e.g. concerning physical activity programs; diet and nutritional programs; etc.) showing that the most effective health programs involve a last stage in which



## **Barriers to and Facilitators of Older Adult's Adherence to Health Recommendations**

*Table 1. Barriers to older adult's adherence to health recommendations across levels of participation/engagement*

<b>Level of analysis</b>	<b>Barriers</b>	<b>Level of participation in which there is a detrimental effect</b>
Macro	<ul style="list-style-type: none"> <li>• Ageist attitudes and behaviours; negative stereotypes associated with a perceived homogeneity of the elderly population group, concerning various aspects of the elderly personal and social life with consequences on engagement and participation (e.g. passiveness, reduced capacities and interests)</li> <li>• Inequalities stemming from socio-demographic, socio-economic, geographical and other factors</li> <li>• Asymmetries of information concerning laws, procedures, and health policies</li> <li>• Communication context as determined by health organizations and other experts/stakeholders (e.g. lack of information sharing; ineffective communication framing and content)</li> </ul>	<ul style="list-style-type: none"> <li>• Consultation</li> <li>• Placation</li> <li>• Partnership &amp; delegated power</li> <li>• Citizen control</li> </ul>
	<ul style="list-style-type: none"> <li>• Lack of resources to effectively engage and participate (e.g. information; professional support)</li> <li>• Over-emphasizing "active ageing" and elderly's autonomy, attributing the responsibility for preserving health to the individuals, rather than to the health care professionals and organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Placation</li> <li>• Partnership &amp; delegated power</li> <li>• Citizen control</li> </ul>
Micro	<ul style="list-style-type: none"> <li>• Communication environment and processes involved in the dyadic patient-health professional interaction (e.g. negative perceived relationship; ineffective communication process and setting)</li> <li>• Characteristics of the health professional/communicator (lack of capacities to convey information, to engage patients, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>• Partnership &amp; delegated power</li> <li>• Citizen control</li> </ul>
	<ul style="list-style-type: none"> <li>• High demanding regimens (e.g. medicine intake rather than lifestyle changes)</li> <li>• Low levels of social and individual resources (e.g. education; income) to adhere to recommendations – objectively available and perceived as available by the elderly</li> <li>• Characteristics of the elderly patient that conflict with collaborative methods (e.g. cognitive impairment; information avoidance; lack of interest/motivation in the communication process)</li> <li>• Characteristics of the communication context (health information perceived as overly complex and/or surpassing the capacity to deliberate on it)</li> </ul>	<ul style="list-style-type: none"> <li>• Partnership &amp; delegated power</li> <li>• Citizen control</li> </ul>

the development of self-regulation competencies is a priority (see Godinho, Alvarez, & Lima, 2013). Naturally, for this to occur, the necessary conditions need to be set, in a preceding stage. A study by Schüz, Wurm, Warner, Wolff and Schwarzer (2013), for example, showed that emphasising health as a subjective motive in older adults is necessary for intentions to be translated into healthy behaviours, via planning. This planning is one of the key features that may allow older adults to implement their intentions into actions and adhere to recommendations, as it may allow finding strategies to cope with barriers and reinforce the facilitators.

The importance of planning in self-management for health behaviours to take place is demonstrated through the Health Action Process Approach (see Schwarzer, 1992, 2008). This approach considers two main phases that need to be implemented, for healthy behaviour to occur - motivational phase and volitional phase – each determined by different factors: The motivational phase emphasizes the importance of (action) self-efficacy, outcome expectancies, and risk perception; the volitional phase emphasizes the importance of both action planning and coping planning, and of self-efficacy maintenance/recovery, for a person to change from an "intender" to an "actor". Planning demands the person to both plan their own behaviour(s) and plan the change in the necessary conditions for it to take place, including overcoming barriers to its implementation and devising (individual and contextual) facilitators for it. Additionally, the person needs to be capable of recovering from failures (e.g. forgetting to take medicine) and having optimistic (self-efficacy) beliefs that they can cope with these barriers (e.g. memory impairments) and recover from failures. All this demands self-regulation strategies, dependant on affective, cognitive and behavioural dimensions. Based on this approach, we consider that the motivational phase is the focus of

the various forms of older people's participation referred before – consultation, placation, partnership and delegated power - as these clearly aim to increase older people's engagement with the healthcare process, i.e. increase their motivation and involvement with the various aspects of it (e.g. patient-health professional relationship; degree of shared decisional power; for a similar perspective, see Cox & Klinger, 2004, with regard to Systematic Motivational Counselling - SMC). However, in our view, the volitional phase can only be reached if the control over the process is placed upon the person. This can only be achieved if a form of Citizen Control (as presented by Arnstein, 1969) is promoted, in which people can self-manage their healthcare process.

A few recent health programs have been trying to reach these goals. One example is the Health and Welfare Information Portal (ZWIP) developed by Robben et al. (2012a) and Robben et al. (2012b) to be an intervention for older people with frailty, based on an online health community (OHC). This aimed at facilitating multidisciplinary communication between health professionals and information exchange in the care of older people. Moreover, it aimed to facilitate self-management and shared decision making between older people and their informal caregivers. This included for example the stimulation of engagement and two-way communication between the patients and a team of health professionals. Moreover, it was supported by strategies for increasing motivation that were tailored to older adults. This was focused on improving self-efficacy and beliefs in the elder's ability to complete the tasks requested and fulfil the pre-determined goals, thus allowing the necessary conditions for self-management to take place. A more recent example in this regard is the SMART-PD program presented by Lakshminarayana et al. (2014), aimed towards the self-management of Parkinson's disease. This program is based on technological assistance from smartphone and internet platforms, including a set of adherence promotion tools. Although still under evaluation, this program may be an effective tool to achieve "citizen control" of their own health, assisted by new technologies. Other examples, have also presented Online Health Seeking (OHS) – "the process by which people find, share and consume online health and wellness information" (Bonner & Mynatt, 2014, p. 1) – as a new trend for interventions focused on adherence and related aspects, based on Patient-Centered Care (PCC) approaches. Various examples (see Bonner & Mynatt, 2014) have shown that PCC may result in positive effects such as improving patient provider relationships and patient's satisfaction with the healthcare process.

It should be noted nevertheless that this type of programs is under development and modification, and still face several barriers (see Makai et al., 2014). First of all, people low digital literacy and low of internet use inhibit the use of OHC. Second, there are various factors that serve as barriers to self-management, even when people are motivated and engaged in the program. Accordingly, Robben et al. (2012a) identified various factors found in the literature, such as: people's attitude toward self-management; emotions (e.g. fear of losing independence); their perceived self-efficacy for self-management; their perceived knowledge (e.g. about the disease, symptoms, and treatments); personal skills and limitations (e.g. cognitive deficits); perceived social norms and social support (e.g. advocacy); financial constraints; and the high complexity of the health care system; the health professionals not providing adequate information for self-management; the health professionals not being genuinely interested in the older person; and lastly the health professionals not encouraging questions. In addition, from the health professional's point of view, various barriers were also identified, such as: their attitude toward patient self-management; their knowledge and skills for self-management support; and others aspects of the health care system<sup>2</sup>. Despite facing several barriers, the types of programs presented emerge as an interesting future path, towards self-regulation as a basis for citizen's control of their own healthcare.

## **CONCLUSION**

From the various aspects referred in the previous sections, it is clear that there is still much work to do in finding strategies that on one side, increase older people's motivation, participation and engagement with the healthcare process and, on another side, provide the necessary conditions for self-regulation, with support/monitoring from formal and informal care providers. Nevertheless, it may be a matter of time, as the various existent programs are being improved and new ones being developed. Longitudinal evaluations of some of these programs (Makai et al., 2014) show that despite the existence of various barriers to their success, there are positive outcomes for the people involved in these (such as e.g. in their activities of daily living). Hence, as long as the necessary conditions are in place (e.g. increase in digital literacy and internet usage, regarding the ZWIP program), older people's motivation and self-management of their own healthcare process may be incremented through more effective two-way communications and self-regulation strategies promotion. Ultimately, this will allow reducing barriers and reinforcing facilitators, towards an increased adherence to health recommendations.

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## KEY TERMS AND DEFINITIONS

**Adherence:** Intentional disposition to implement actions as prescribed in a recommendation(s) communicated by health professionals (e.g. taking medication) and/or organizations (e.g. recommended amount of nutrients intake).

**Barriers:** factors that may inhibit individual's intentions to adhere and reduce the probability of implementing these intentions into behaviours (actual adherence).

**Facilitators:** factors that may reinforce individual's intentions to adhere and increment the probability of implementing these intentions into behaviours (actual adherence).

**Deliberation:** Dispositional tendency to actively and consciously approach one-self (behaviourally, cognitively and/or emotionally) from information that is deemed personally relevant.

**Engagement:** Active involvement and participation in the different aspects of the healthcare process in general and health recommendations communication process in particular. This can have various manifestations, such as interest in information, information seeking behaviours, positive interactions with the health professionals and others.

**Information Avoidance:** Dispositional tendency to actively and consciously distance one-self (behaviourally, cognitively and/or emotionally) from information that may pose a threat to ones perceptions, beliefs and evaluations toward one or more issues.

**Motivation:** "The internal states of the organism that lead to the instigation, persistence, energy, and direction of behaviour towards a goal" (Klinger & Cox, 2004; p. 3).

**Participation:** Set of principles and practices aimed at complementing representative democracy, yet different from forms of direct democracy, such as petitions and referendums. This includes a wide range of experiences setting new spaces of legitimized deliberation between political institutions and civil society beyond the traditional adversary model of political debate.

## ENDNOTES

<sup>1</sup> More information on the Seventh Framework Programme funded Project MOPACT – Mobilising the Potential of Active Ageing in Europe is retrievable on: [www.mopact.group.shef.ac.uk](http://www.mopact.group.shef.ac.uk)

<sup>2</sup> For the full list of studies references, please see Robben et al. (2012a).